

National Library of Medicine Strategic Plan for Addressing Health Disparities 2002-2006

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National Library of Medicine

NLM Mission/Vision Statement

Over the past half century, the nation's investment in scientific research has resulted in unprecedented revolutionary progress in biological, medical, and material sciences. Information technology holds the promise of delivering specific knowledge in a timely manner to billions of people worldwide, in ways undreamed of even a short time ago. The National Library of Medicine (NLM), in pursuit of its longstanding mission to acquire, organize, and disseminate health-related information, now has the opportunity to provide near-instantaneous reliable access to high quality health information resources when and where decisions are made. The support of NIH's efforts to understand and eliminate health disparities between minority and majority populations is an integral part of NLM's mission.

Overview of NLM Strategy for Addressing Health Disparities

NLM is directing many of its efforts toward remedying the disparity in health opportunities experienced by important segments of the American population. These efforts are based on the belief that improving access to affordable and easy-to-use health-related information (in the form of published literature, databases, and the authoritative content of others) can help solve health disparities. Collection and database development is critical to this. The advanced information products and services of the National Library of Medicine are built on the foundation stone of its unparalleled collections. The Library today is seen as a principal source of biomedical information and the NLM's many high-technology programs are infused with the confidence and competence resulting from a century and a half of experience in filling the information needs of health professionals. The Library continues to place primary emphasis on its role as acquirer, organizer, and disseminator of health-related information.

The Library is devoting considerable attention and resources to improving access by health professionals, patients, families, community-based organizations, and the general public to information, with special emphasis on rural, minority, and other underserved populations. NLM firmly believes that improved access to health information in MEDLINE, MEDLINEplus, *ClinicalTrials.gov*, and the Library's other computerized databases will result in higher quality health care for the Nation's citizens.

In the following areas of emphasis, NLM utilizes a number of strategies to ensure access to health-related information:

- Improving the information infrastructure and communications capabilities of minority communities.
- Employing communication methods that are racially and culturally sensitive and appropriate.
- Increasing the scope of information products and services to include cultural, psychological, behavioral, social, gender-based and environmental influences.
- Building partnerships with community-based and professional organizations.

Community Outreach, Information Dissemination, and Public Health Information

Areas of Emphasis

Initiative 1. Improve delivery of web based information, through the development of easy-to-use information resources such as MEDLINEplus and *ClinicalTrials.gov* that are sensitive to cultural diversity issues, educational level, and language.

Rationale and Priority

In 1998, NLM began to provide health information to consumers through a new website, MEDLINEplus. This was in direct response to data which showed that NLM's MEDLINE database, available free on the web since June of 1997, was being searched by members of the public seeking health information for themselves and their families. It was estimated at that time that 30% of searches were being done by the public. Although many members of the public are able to obtain useful information from the research literature covered in MEDLINE, it is not the most appropriate place for most citizens to seek health information. In response to this need, NLM developed MEDLINEplus, guided by continuous input from its users and an NIH Advisory Group.

MEDLINEplus is a resource that health professionals and especially consumers can depend on for information that is authoritative and up to date. It provides access to information produced by the National Library of Medicine, such as preformatted searches of MEDLINE, plus links to information produced by the National Institutes of Health and other trusted sources on about 500 diseases and conditions. A database of full-text drug information, an illustrated medical encyclopedia, lists of hospitals and

physicians, dictionaries, health information in Spanish, extensive information on prescription and nonprescription drugs, health information from the media, and links to thousands of clinical trials through *ClinicalTrials.gov* are also included. MEDLINEplus is updated daily. Our emphasis is on organizing the full-text publications produced by the NIH Institutes and other federal government organizations.

A recent survey of MEDLINEplus users indicated that there is a very high level of satisfaction with the service, but the service is reaching disproportionately fewer members of minority populations. In addition, input from public libraries and community groups indicates that more information is needed in Spanish to reach the Hispanic population, and there is need for additional information to reach low literacy populations. Both of these are high risk populations for health disparities, as are members of other minority and low income groups. NLM's goal is to continue to develop and test new ways of presenting the website that will enhance its appeal and usefulness to these populations and to identify and link to additional resources that will meet their special health information needs. The intended outcome is for MEDLINEplus to become a major web resource for health information for those impacted by health disparities so that they will have access to the same quality health information as the rest of the population. A key component of this strategy is to work through NLM's National Network of Libraries of Medicine to reach libraries, community groups, faith based organizations, disease support and self help groups, and others, so that the public will know where to go to find current, accurate, and understandable health information and clinical trials.

Objectives

The major objectives in NLM's proposed five-year program include:

- Conduct research into the health information needs of minority populations who are using the internet to find information for themselves or family members;
- Identify and obtain additional content appropriate for reaching minority and low literacy populations;
- Investigate and test new ways of presenting the MEDLINEplus and *ClinicalTrials.gov* website so that it meets their health information needs;
- Work with libraries, community, faith based and other organizations, and consumer advocacy groups to ensure that these resources are available, known, and used;

- Test new ways of reaching these populations and evaluate their effectiveness.

Action Plan

- Conduct studies of minority users of health resources on the Internet to assess their information needs and use patterns;
- Identify and make additional non-English resources available on MEDLINEplus;
- Identify and make available on MEDLINEplus and *ClinicalTrials.gov* additional health information which is sensitive to culturally diverse groups;
- Collaborate with NIH Institutes to identify topics needing Spanish translation and encourage increased emphasis in this area;
- Develop additional interactive tutorials aimed at reaching low literacy and Spanish speaking users;
- Develop and test Spanish interface to MEDLINEplus;
- Conduct usability testing of MEDLINEplus and *ClinicalTrials.gov* with minority and low literacy users;
- Disseminate information about MEDLINEplus and *ClinicalTrials.gov* to health professionals, health care organizations, libraries, health care, community, faith based, and other organizations who work with minority and low income populations;
- Exhibit at national meetings of minority health professional organizations and national groups which have a minority focus;
- Fund projects with libraries, community, faith based and other organizations that reach out to minority and low income populations to improve their access to health information.

Timeline

FY 2002-2003	Conduct minority focus groups
	Add Spanish medical encyclopedia to MEDLINEplus
	Develop Spanish interface to MEDLINEplus

	Conduct usability study of Spanish interface
	Develop Spanish language promotional materials
	Evaluate use of Spanish language site
FY 2003-2006	Conduct additional minority user studies
	Identify and add additional culturally sensitive information to MEDLINEplus and <i>ClinicalTrials.gov</i>
	Conduct usability testing with additional populations
	Evaluate use and satisfaction with MEDLINEplus and <i>ClinicalTrials.gov</i>
FY2002-2006	Add additional interactive tutorials to MEDLINEplus
	Continue collaboration with other NIH institutes on content of MEDLINEplus
	Add additional non-English content to MEDLINEplus
	Fund projects targeting minority groups and health disparities through NN/LM contracts, subcontracts, purchase orders and other mechanisms
	Exhibit at national and regional meetings targeting minority groups and those focusing on health disparities
	Develop new partnerships with community groups and other organizations to improve access to health information in minority populations

Performance Measures

- Number of focus groups with minority populations
- Number of hits to Spanish medical encyclopedia
- Number of hits to Spanish interface to MEDLINEplus
- Number of usability studies conducted with minority and low literacy populations

- Number of Spanish language promotional materials distributed
- Number of additional links to Spanish language materials
- Number of additional Spanish language interactive tutorials provided
- Number of additional English language interactive tutorials provided
- Number of additional links to materials in health disparity focus areas
- Number of additional links to other non-English materials
- Number of projects funded which target minority groups and health disparities
- Number of exhibits at national and regional meetings which target minority groups and health disparities

Outcome Measures

- Results of focus groups translated into approaches to reaching the targeted populations
- Increased use of MEDLINEplus by minority populations
- Usability study results and user feedback used to guide development of MEDLINEplus
- Satisfaction levels of minority users of MEDLINEplus
- Evaluations of funded projects which target minority groups and health disparities

Initiative 2. Promote improved access to HIV/AIDS information to health professionals, patients, the affected community and their caregivers, as well as the general public in minority communities.

Rationale and Priority

NLM is continuing to expand efforts to improve access to HIV/ AIDS information to patients, the affected community and their caregivers, as well as the general public. A comprehensive AIDS information service is vital to enable people to combat the AIDS epidemic. Scientists, physicians, educators, and other health professionals need rapid access to the latest information on AIDS research, diagnosis, treatment, control, and prevention. Consumers

require similar access to appropriate information for decision-making about their behavioral choices and treatment. Community-based organizations, clinics and other types of service providers also need access to high quality, accurate and timely information for their staff and clients. NLM initiated its efforts to work with consumers based upon recommendations from a joint NLM/OAR sponsored conference held in 1993 designed to elicit input from the community about needed services and resources. Since that time interactions with representatives of AIDS community-based organizations have indicated that there is a continued need for quality information products and services, training, and funding for local efforts to improve access. As the epidemic has expanded further into minority communities, the need for resources and training has increased significantly, rather than decreased. NLM is now working with grassroots organizations that focus on the immediate needs of socioeconomically disadvantaged minorities to assist in developing infrastructure for information access. The goal is to enable organizations to provide access to quality information resources to their clients, staff, and community, as well as to incorporate the use of accurate information into the routine conduct of their business.

Objectives

The major objectives in NLM's AIDS outreach and training program include:

a) Providing an annual funding program to enable community organizations, health departments, and libraries to provide access to electronic resources, training in the use of these resources, expanding collections, Internet connections, development of locally specific information materials, town hall meetings, and opening access to collections and document delivery services. (2) Updating HIV/AIDS information resources with Spanish language enhancements, including translations of titles and summaries of clinical trials, development of training resources and supporting materials, translation of the current glossary, and other related enhancements to make HIV/AIDS databases more useful to Hispanic communities. (3) Training courses for faculty, staff and students at HBCUs, Minority Educational Institutions, and their local communities in accessing and using electronic HIV/AIDS resources

Action Plan

- Issue RFQ for AIDS Community Information Outreach Program
- Publicize and promote AIDS Community Information Outreach Program and encourage proposal submissions

- Work with community organizations to promote an understanding of the role of information and information access in fighting AIDS
- Formalize a collaboration with the United Negro College Fund Special Programs (UNCFSP), Inc. to train faculty and staff in the use of NLM's electronic information resources.
- Work with UNCFSP to develop selection criteria for faculty initiated information projects and curricula.
- Host a meeting for faculty and staff from UNCFSP member schools about project and NLM programs and services.
- Make competitive awards as part of UNCFSP project; monitor awards; review progress; modify as appropriate
- Expand UNCFSP program, to additional schools
- Work with minority educational institutions and other government agencies to co-sponsor conferences with opportunities for training workshops and information dissemination
- Conduct presentations and training sessions at meetings of minority health professionals such as the Black Nurses Association
- Conduct training courses at HBCUs, Hispanic Serving Institutions, Tribal Colleges and other institutions with high minority populations. Invite participation in these training courses by representatives of local community organizations

Timeline

FY 2002	Formalize collaboration with UNCFSP Develop selection criteria for UNCFSP projects
FY 2002 – 2003	Hold meeting with UNCFSP faculty and staff Solicit and award first round of funding for UNCFSP information projects
FY 2003 – 2006	Monitor, evaluate and modify UNCFSP program

	Continue UNCFSP funding program
FY 2002 – 2006	Sponsor conferences Conduct presentations and training courses
FY 2002-2006	Provide awareness opportunities and training to community organizations Encourage participation in activities and programs offered
FY 2002 – 2006	Issue AIDS Community Information Outreach solicitation annually Encourage participation in program by community-based minority organizations

Performance Measures

- Number of community-based organizations submitting proposals
- Number of faculty, staff and students trained from minority educational institutions
- Number of training courses held at HBCUs, minority institutions, or at minority health professional conferences/meetings
- Number of projects funded at minority institutions

Outcome Measures

- NLM plans to measure impact and outcomes by tracking new awards made and analyses/findings disseminated by awardees and staff.

Initiative 3. Expand activities with the Historically Black Colleges and Universities (HBCUs) to provide information about toxicology, environmental health, and hazardous waste to include more broadly members of minority and low socioeconomic communities.

Rationale and Priority

The environmental justice movement took shape in the early 1980s, questioning inequities in the distribution of toxic waste sites that activists asserted were disproportionately located in minority and other low-income areas. In 1987, the United Church of Christ published a study, *Toxic Waste*

and Race in the United States, calling attention to the association between hazardous waste facilities and the racial/socioeconomic composition of the communities hosting such facilities. The study reported that while economic status played an important role in the nationwide location of commercial hazardous waste facilities, the race of the residents proved to be a more significant determinate.

In 1990, then-Governor Clinton of Arkansas organized a group of seven governors to assess the state of the environment in the Delta Region covering 219 counties between Illinois and the Gulf of Mexico. A result of this initiative was the Mississippi Delta Project, an objective of which was to create partnerships among government, academia, private sector organizations, and community residents. Through these partnerships efforts were made to identify key environmental hazards, promote environmental quality, and reduce and, where possible, prevent these hazards from impacting on health and the environment. Emphasis was placed on affected persons in underserved communities. The National Library of Medicine was one of the federal agencies and institutes cooperating in the Mississippi Delta Project.

Objectives

The initial mission of this project was to strengthen the capacity of Historically Black Colleges and Universities (HBCUs) to train health professionals to use NLM's Toxicology and Environmental Health Information Program databases. Instructional resources were to be developed to support academic programs such as: 1) educational tools to increase awareness of information resources available, 2) instructional tools for teaching students and faculty how to use these information resources, and 3) a new mechanism to reach minority and underserved communities to increase their understanding of risks associated with exposure to toxic and hazardous chemicals

As a result of this project online searching has been integrated into the curricula at many of the HBCUs involved in the pilot project. Even further, several of the HBCUs have used this exposure to electronic information resources to implement programs in medical informatics. To date, over 80 HBCUs have participated in the extended project and training is continuing at HBCUs throughout the country. Reports from many of the HBCUs indicate that the awareness and interest generated by this training has enabled them to work collaboratively with other institutional components to bring these NLM resources as well as access to the Internet to their institutions.

To further extend the impact of this effort and to address the concerns about health disparities that may be associated with race, socioeconomic status, environmental factors, etc., this effort will be expanded from the HBCUs to include more broadly members of minority and low socioeconomic communities as well as other educational institutions serving minority populations.

NLM has expanded its work with HBCUs in breadth and scope as well as in size. TIOP's membership has recently been expanded to include the University of Puerto Rico Medical School in San Juan, Puerto Rico and the Oglala Lakota College in South Dakota to bring in participation of other minority schools. In addition to its initial focus on toxicology and environmental health, other health disparities have been added representing a broader perspective of minority health.

Librarians from a dozen HBCUs and other Minority Institutions were brought together to provide advice to NLM in the development of new programs for working with minority health professionals and consumers. These librarians, primarily from the schools that NLM has worked with in the past through the Toxicology Information Outreach Program, were asked to assist NLM in developing appropriate partnerships to move programs forward and improved access to and use of relevant information resources in currently underserved communities. NLM will be following up with these librarians to develop specific projects based upon these discussions.

NLM is looking for additional opportunities to work with HBCUs and is implementing a project with the United Negro College Fund as a way to reach not only the faculty and students of the schools, but health information consumers as well.

Action Plan

- Collaborate with HBCUs, tribal colleges, and Hispanic Serving Institutions to hold training courses for faculty, staff and students
- Collaborate with professional organizations of minority health professionals to hold training courses
- Identify minority community-based organizations to collaborate with for training and information dissemination
- Disseminate information about NLM's resources and services
- Develop materials for use by minority organizations, institutions, and health professionals

- Conduct presentations at conferences
- Sponsor or co-sponsor conferences and meetings to create opportunities to raise awareness and disseminate information.
- Encourage/fund the development and implementation of local information access or information use programs and projects

Timeline

FY 2002-2006	Collaborate with HBCUs, tribal colleges, and Hispanic Serving Institutions to hold training courses for faculty, staff and students
FY 2002-2006	Collaborate with professional organizations of minority health professionals to hold training courses
FY 2002-2004	Identify minority community-based organizations to collaborate with for training and information dissemination
FY 2002-2006	Disseminate information about NLM's resources and services
FY 2002-2006	Develop materials for use by minority organizations, institutions, and health professional
FY 2002-2006	Sponsor or co-sponsor conferences and meetings to create opportunities to raise awareness and disseminate information.
FY 2002 - 2006	Encourage/fund the development and implementation of local information access or information use programs and projects

Performance Measures

- Number faculty, staff, students, community members trained

- Number of items developed
- Number of conferences sponsored
- Number of conference attendees
- Number of new projects developed

Outcome Measures

- Ongoing qualitative assessment of TIOP
- User satisfaction with training
- Tracking new projects supported and analyses of progress.

Initiative 4. Train minority health professionals, information professionals, and community members to use NLM and other quality health information resources

Rationale and Priority

NLM recognizes that it is critical to establish relationships with health professionals, information professionals and members of organizations that encourage and foster communication and information access in local communities and with different segments of the population. It is of particular interest to ensure that the government is meeting the needs of minorities and underserved communities.

Access to the latest and best information is essential to medical decision-making for patients and their providers. Despite its tremendous potential, many members of minority communities do not have access to electronic information resources. Many minority health professionals serve in their own communities and also may lack access to or knowledge of these important resources.

Objectives

NLM is approaching this program on a number of fronts. The five ethnic caucuses of the American Library Association (the American Indian Library Association, the Asian Pacific American Library Association, the Black Caucus of the American Library Association, the Chinese American Library Association and Reforma), the Office of Literacy and Outreach Services, ALA, and the National Library of Medicine will offer a preconference on minority health information at the 2002 ALA Annual Meeting in Atlanta, GA. The

preconference will provide attendees with information that will increase their awareness of NLM's resources and services and skills that will allow them to better serve diverse populations in the area of health information. The five ethnic caucuses, OLOS and the NLM believe that the sharing of health information and knowledge within communities of color will result in improved health outcomes for diverse populations. The preconference will serve as the first step in building awareness of health information for minority librarians. Future projects will arise from needs identified at this conference.

Another mechanism that NLM is using to identify needs is through the librarians at the health sciences libraries of minority educational institutions. These librarians and their libraries service minority health professionals, students, and their communities and are uniquely situated to provide this input to NLM. NLM then uses this information to create products, programs, and services.

To facilitate access to and delivery of health science information through computers and telecommunication technology for health care providers, NLM is initiating a training program with the National Medical Association (NMA). Improving the ability of NMA's members to use quality health information resources, including those from NLM, will enable them to remain current in their area of specialty, conduct medical research, improve patient care, involve their patients in clinical trials, and provide consumer level information for their patients. The initial plan is for NLM to provide training courses at NMA regional meetings to introduce physicians and their staffs to health information databases and other electronic resources and services. Later phases of this project will include working with additional health professional organizations.

NLM has funded pilot projects to improve access to consumer health information for community-based organizations. These two-year projects have just started and will be closely observed by NLM. The feedback provided during the next two years will assist NLM with designing outreach projects designed to involve minority community-based organizations in the development of local programs of health information dissemination.

Action Plan

- Collaborate with the American Library Association Ethnic Caucuses to provide conference support for health information programming
- Plan and carry out an ALA preconference on minority health information resources and services.

- Collaborate with the National Medical Association to plan and conduct training activities at regional meetings
- Identify additional health professional groups and associations with which to collaborate
- Conduct presentations or training activities at meetings of health professionals and health information professionals
- Assess progress, barriers, outcomes of pilot minority consumer health outreach projects and refine program
- Provide funding opportunities for local information access projects in minority communities.

Timeline

FY 2002-2003	Plan and carry out an ALA preconference on minority health information resources and services.
FY 2002-2003	Collaborate with the National Medical Association to plan and conduct training activities at regional meeting
FY 2003-2004	Identify additional health professional groups and associations with which to collaborate
FY 2003-2006	Conduct presentations or training activities at meetings of health professionals and health information professionals
FY 2003-2004	Assess outcomes of pilot minority community outreach projects and determine direction for future programs
FY 2004-2006	Provide funding opportunities for local information access projects in minority communities

Performance Measures

- Number trained
- Number of training sessions
- Feedback from pre- and post- training surveys
- Number and types of projects funded

Outcome Measures

- Strategies for information dissemination in minority communities
- Improved access to information

Initiative 5. Develop a set of population-specific mini web sites that focus on the issues of particular populations or geographic areas**Rationale and Priority**

Special populations have special needs for health information. The National Library of Medicine has created a Web site aimed at the special needs of the inhabitants of the Arctic (<http://arctichealth.nlm.nih.gov>) This web site provides access to evaluated health information from hundreds of local, state, national, and international agencies, as well as from professional societies and universities. The site has sections devoted to chronic diseases, behavioral issues, traditional medicine, environment/pollution, and environmental justice, as they apply to populations of the arctic region. The National Library of Medicine is now working with the Regional Medical Library at the University of Washington in Seattle to have ArcticHealth maintained by a university already working with issues important to the Arctic region. This is first in a series of planned health information Web sites for special populations. Others planned include sites for Asian/Pacific Islander Health and Hispanic Health.

Objectives

NLM's goal includes the development of a series of web sites that will serve the needs of policy makers, researchers, health providers, and members of the communities involved. The web sites may serve as focal points for gathering into one place important information about the health care issues and research relevant to that population or area. NLM will enter into

partnerships with local or other significant groups to maintain the web site and potentially expand it to serve additional needs of the constituents.

Action Plan

- Identify special populations or subpopulations (e.g., African American Seniors) as targets for these web sites
- Develop web site
- Identify and negotiate with local university, library, or other type of organization to maintain the web site and develop accompanying materials and outreach plans
- Continue to monitor and assess web sites

Timeline

FY 2002-2006	Identify target populations for web sites
FY 2002-2004	Design and develop web sites
FY 2002-2004	Negotiate with local group for web site maintenance
FY 2003-2006	Test and evaluate sites

Performance Measures

- Number of page views
- Number of unique users
- Number of inquiries

Outcome Measures

- Improved access to population-specific information
- Associated projects/programs developed

Initiative 6. Develop an internship program for community leaders**Rationale and Priority**

To develop and implement an internship program for representatives from community-based organizations to learn (1) about NLM's programs and services, (2) how to use information resources and integrate them into their programs, (3) information technology, (4) information dissemination. The interns would study successful community-based projects funded by NLM and develop ideas on how to involve their community in this process.

NLM's experience with community organizations indicates that these organizations are ill equipped to initiate and carry out information service activities. They are not likely to have the expertise required to apply for funding or provide training in the use of information resources and services. An information internship for staff from minority organizations may provide the needed experience and understanding to enable these organizations to take advantage of government programs and resources.

Objectives

The objective for this project is to provide an opportunity for representatives from minority community organizations to learn about the National Library of Medicine, the National Network of Libraries of Medicine, and successful information projects currently underway. This project will not only provide training in the use of information resources, instruction in managing information outreach projects, information about potential opportunities, but most importantly, connection with people and programs that might provide support and assistance in the future.

Action Plan

- Plan curriculum for internship
- Identify first participants
- Conduct internship
- Continue to monitor and assess progress
- Adjust curriculum based upon feedback
- Identify methods and criteria for selecting new interns

Timeline

FY 2002-2003	Plan curriculum
FY 2002-2004	Identify initial Interns
FY 2002-2006	Carry out internship with ongoing assessment and feedback

Performance Measures

- Attendance at scheduled sessions
- Positive feedback from interactions

Outcome Measures

- Successful project proposal for NLM funding
- Successful local projects

Initiative 7. Develop a plan to enhance the competitiveness of minority organizations and institutions and those that serve minority and underserved populations in seeking NLM funding.

Rationale and Priority

NLM offers various funding opportunities through many of its divisions, i.e. Extramural Programs, Specialized Information Services, Telemedicine initiatives, and the NN/LM. NLM plans to increase its efforts to provide assistance to minority organizations and institutions and organizations that serve minority and underserved populations in applying for NLM funding and responding to Requests for Proposals. The 4500 health sciences libraries in the NN/LM, which are a key component in NLM's outreach efforts to address the health disparities in minority and underserved populations, can provide valuable assistance in these efforts. The NN/LM can work with program areas to develop and provide assistance in conducting technical assistance workshops. Particular attention will be paid to finding ways to expand NLM Information Access and Internet Connections grant programs to improve information access and internet connectivity for minority-serving institutions and organizations.

Objectives

- Work with NLM program areas to develop technical assistance workshops
- Identify groups to which to offer technical assistance workshops
- Assist in the development of materials for the workshops
- Assist in the promotion of the workshops

Action Plan

- •Conduct technical assistance workshops prior to the issuance of RFPs and RFAs
- •Develop materials based on the program areas issuing RFPs and RFAs
- •Disseminate information on workshops to targeted organizations
- •Develop a mechanism to track which targeted organizations/institutions applied for NLM funding following attendance at workshops

Timeline

FY 2002-2006	Identify targeted groups
	Gather information on workshops held by other NIH Institutes and Centers
	Develop plan to present workshops
	Present workshops

Performance Measures

- Number of targeted organizations/institutions participating in workshops
- Number of individuals trained
- Number of workshops held

Outcome Measures

- Increased number of targeted organizations/institutions receiving training in grant writing

- Increased number of targeted organizations/institutions applying for NLM funding
- Increased number of targeted organizations/institutions eligible for NLM funding

Initiative 8. Improve the Internet infrastructure for American Indians and Alaska Natives in selected geographic areas so as to facilitate or upgrade tribal access to web-based biomedical and health information.

Rationale and Priority

NLM seeks to continue its groundbreaking program to improve access to and use of health information by Native Americans. The program began about three years ago with an emphasis on select American Indian reservations and Alaska Native villages in the Pacific Northwest. Subsequently, NLM extended the program to select Indian reservations in the Pacific Southwest, and one site in the Mid-Atlantic. Also, in the last year, NLM participated in the NIH Acting Deputy Director's American Indian Pow-Wow Initiative, and exhibited at all five selected pow-wows in the Mid-Atlantic region. The intended results of these combined activities are to: help increase awareness and understanding of health information resources among Native Americans; establish or enhance the Internet connectivity and technical infrastructure needed to access such information; strengthen the capacity of tribal communities to make best use of health information resources; assist Native Americans in improving their health information seeking behaviors; and ultimately contribute to improvements in Native American health behaviors and outcomes.

The Tribal Connections program emerged in part from NLM's 1996 review of its outreach programs. The review concluded that Native Americans had not received adequate priority within NLM's overall efforts to address the needs of minority and underserved communities. The importance of Tribal Connections was reinforced through two project advisory committee meetings, feedback from other governmental and non-profit organizations with an interest in this area, and input received as part of NLM's long-range planning process. Also, various tribal leaders and groups have affirmed the need for Tribal Connections. Additionally, health statistics indicate that Native Americans have disproportionately high rates of various diseases and conditions such as diabetes.

Objectives

The major objectives in NLM's proposed five-year (FY02-06) Tribal Connections program include: a) completion of the evaluation of what has been known as Tribal Connections Phases I-II; b) enhanced follow-up and evaluation at select Phase I-II sites (this effort is known as Phase III); c) phased extension of Tribal Connections to other areas of the country; d) continuation and extension of the Pow-Wow Initiative in select geographic areas; e) upgrading and enhancement of the Tribal Connections web site; and f) further refinement and implementation of the overall Tribal Connections evaluation strategy.

Action Plan

The proposed action plan is intended to carry out the above objectives and accomplish the intended results of the Tribal Connections Program.

TASK:

A-1. Complete Phase I-II Evaluation, in collaboration with the Pacific Northwest Regional Medical Library (University of Washington, Seattle).

B-1. Conduct Enhanced Follow-up with Select Phase I-II Tribal Sites, in collaboration with the Pacific Northwest Regional Medical Library and select tribal organizations.

B-2. Plan and Conduct Evaluation of Enhanced Tribal Follow-up, in collaboration with the Pacific Northwest Regional Medical Library.

C-1. Develop Plan for Phased Extension of Tribal Connections to Other Geographic Areas.

C-2. Implement Extension Plan on a Phased Basis at Select Tribal Sites, with Select Collaborating Institutions.

D-1. Develop Plan for Extension of Indian Pow-Wow Initiative, in collaboration with the Office of the NIH Acting Deputy Director.

D-2. Implement Extension Plan on a Phased Basis at Select Pow-Wows, with Select Collaborating Institutions.

E-1. Develop Plan for Upgrading of Tribal Connections Web Site.

E-2. Implement Web Site Upgrade Plan.

E-3. Evaluate Web Site Upgrade.

F-1. Develop Plan for Refined Overall Tribal Connections Evaluation Strategy.

F-2. Implement Refined Evaluation Strategy.

Timeline

Time Frame	Task (see above)	Brief Description
FY 2002	A-1	Complete Phase I-II evaluation
	B-1	Conduct enhanced follow-up
	C-1	Develop tribal extension plan
	D-1	Develop pow-wow extension plan
	E-1	Develop tribal web site upgrade plan
FY 2003	B-1	Continue enhanced follow-up
	B-2	Plan follow-up evaluation
	B-2	Conduct follow-up evaluation
	C-2	Implement tribal extension
	D-2	Implement pow-wow extension
	E-2	Implement web site upgrade
FY 2004	F-1	Develop refined evaluation strategy
	C-2	Continue tribal extension
	D-2	Continue pow-wow extension
	E-3	Evaluate web site upgrade
FY 2005	C-2	Continue tribal extension
	D-2	Continue pow-wow extension

	F-2	Implement refined evaluation
FY 2006	C-2	Continue tribal extension
	D-2	Continue pow-wow extension
	F-2	Complete refined evaluation

Performance Measures (Process variables)

- Number of reports completed: planning, implementation, evaluation.
- Number and type of persons engaged in tribal/site level planning.
- Number of training sessions conducted.
- Number and type of participants in training sessions.
- Number and type of special activities supported: outreach activities, pow-wows, health fairs.
- Number and type of participants in special activities.
- Number of current (Phase I-II) tribal sites engaged in intensive follow-up.
- Number of new tribal sites engaged in tribal connections program.
- Number of new or enhanced tribal connections partnerships.
- Number of new or enhanced computer access terminals, local and wide area networks, and Internet connections.

Outcome Measures (Outcome variables)

- Levels of tribal awareness of web-based health information resources relevant to tribal health concerns.
- Levels of satisfaction with and efficacy of the tribal connections planning process--as viewed by the relevant tribal staff and leadership.
- Levels of satisfaction with and efficacy of the tribal connections web site, training, and special activities--as viewed by the participants.
- Changes in the quality and performance of the tribal technical infrastructure needed to support.

- Changes in usage levels for the upgraded tribal connections web site, and other relevant web sites, by participants in training sessions and special activities.
- Changes in health information seeking behavior of participants in training sessions and special activities.
- Changes in health behavior and, to the extent measurable, health decisions and outcomes of participants in training sessions and special activities.
- Changes in overall capacity of the participating tribal communities to make use of health information resources to enhance the health of the community.

Initiative 9. Explore the use of new information technologies to enable diabetes patients to manage their disease and avoid or delay the onset of costly and debilitating complications, especially patients from minority and medically underserved populations.

Rationale and Priority

NLM is actively exploring the use of new information technologies to enable diabetes patients to manage their disease and avoid or delay the onset of costly and debilitating complications, especially patients from minority and medically underserved populations.

In particular, we seek to learn how the use of NLM's MEDLINEplus web site, and other computer-based health information resources, can be helpful to patients, their families, and member of the public to learn about and understand the latest research news on diabetes, nutritional requirements, tests, devices, secondary prevention techniques, and for obtaining answers to patient-specific questions. In the clinical setting, the principal hypothesis is that MEDLINEplus can reinforce and supplement the information provided by physicians, nurses and health educators. A related hypothesis is that a combination of individualized training, and access to publically available computer resources at hospital libraries and elsewhere in the community can help bridge the "digital divide" experienced by minority populations that have less ready access to computers in the home, school and workplace than the majority population.

Objectives

Develop, design, implement and evaluate a comprehensive program of diabetes-focused outreach initiatives in collaboration with academic health

science centers and libraries, clinical centers, community-based organizations and voluntary health organizations.

Project A. In collaboration with the Naomi Berrie Diabetes Center at Columbia/Presbyterian Hospital in New York City, study the benefits of MEDLINEplus and the Center's own website with Hispanic and African-American teenage Type 1 diabetes patients who are on the insulin pump. These new resources are intended to reinforce and supplement the information provided by the Center's physicians, nutritionists and educators. The Center is also working with the medical informatics department at Columbia to build a Type 1 diabetes module for a promising telemedicine system now under development for patients and hospital staff.

Project B. In collaboration with the Childrens Hospital of Los Angeles, study how a diverse patient population of Hispanic and African-American teens and the families of newly diagnosed Type 1 patients can benefit from using MEDLINEplus to learn about and understand the latest research news, nutritional requirements, and uses of new medical devices for promoting better diabetes management and control.

Project C. In collaboration with the Medical University of South Carolina health sciences library, study how third year medical students and their preceptors equipped with portable laptop computers can use the technology to access needed diabetes and other health information at the time of need. The students are enrolled in a clerkship that serves rural indigent patients, many of whom suffer from Type 2 diabetes and its complications.

Project D. Follow-up with the King/Drew Medical Center in Los Angeles and their efforts to promote continuity of care with the aid of a diabetes 'smart card' that enables access to a centralized medical record and diabetes-related test results for a Type 2 Hispanic and African-American population that is seen variously at different health centers across the county.

Project E. In collaboration with the University of Texas Health Science Center at San Antonio, and at its regional health center and clinics in the Lower Rio Grande Valley, study how a computer workstation installed in the clinic waiting room can provide Hispanic patients with diabetes-related information. The health care providers to encourage use of MEDLINEplus will use prescription pads

Project F. Collaborate with the Juvenile Diabetes Research Foundation in a variety of mutually supportive uses of new information technologies. These include enhancement of NLM's MEDLINEplus diabetes content for children and teens; user evaluations of MEDLINEplus; inclusion of JDRF-sponsored

trials in NLM's ClinicalTrials.gov database; creation of Spanish language resources based on JDRF's *Countdown* research magazine; experimentation with informatics tools to lessen the probability of misdiagnosis of Type 1 diabetes, particularly in emergency departments serving minority and other medically underserved populations; experiment with informatics and distance education tools for science teachers and nurses in low income high schools.

Timeline

FY 2002	Projects A,B,C,D,E,F
FY 2003	Projects A,C,D,E,F
FY 2004	Project F and others TBD
FY 2005	Project F and others TBD
FY 2006	Project F and others TBD

Performance Measures (Process Variables)

- Number and quality of new outreach project initiatives funded.
- Number of reports completed: planning, implementation, and evaluation.
- Number and type of persons enrolled in studies.
- Number and type of participants in training sessions.
- New diabetes-related information added to MEDLINEplus and ClinicalTrials.gov
- User satisfaction with MEDLINEplus and ClinicalTrials.gov
- Number of user accesses, page hits, and searches of MEDLINEplus and ClinicalTrials.gov

Outcome Measures (Outcome Variables)

- Changes in knowledges, attitudes and skills related to diabetes management.
- Changes in patient behaviors related to ADA-recommended guidelines.

- Changes in reported and observed measures of patient self-efficacy.
- Changes in clinical measures of diabetes control (i.e., blood sugar, A1c).